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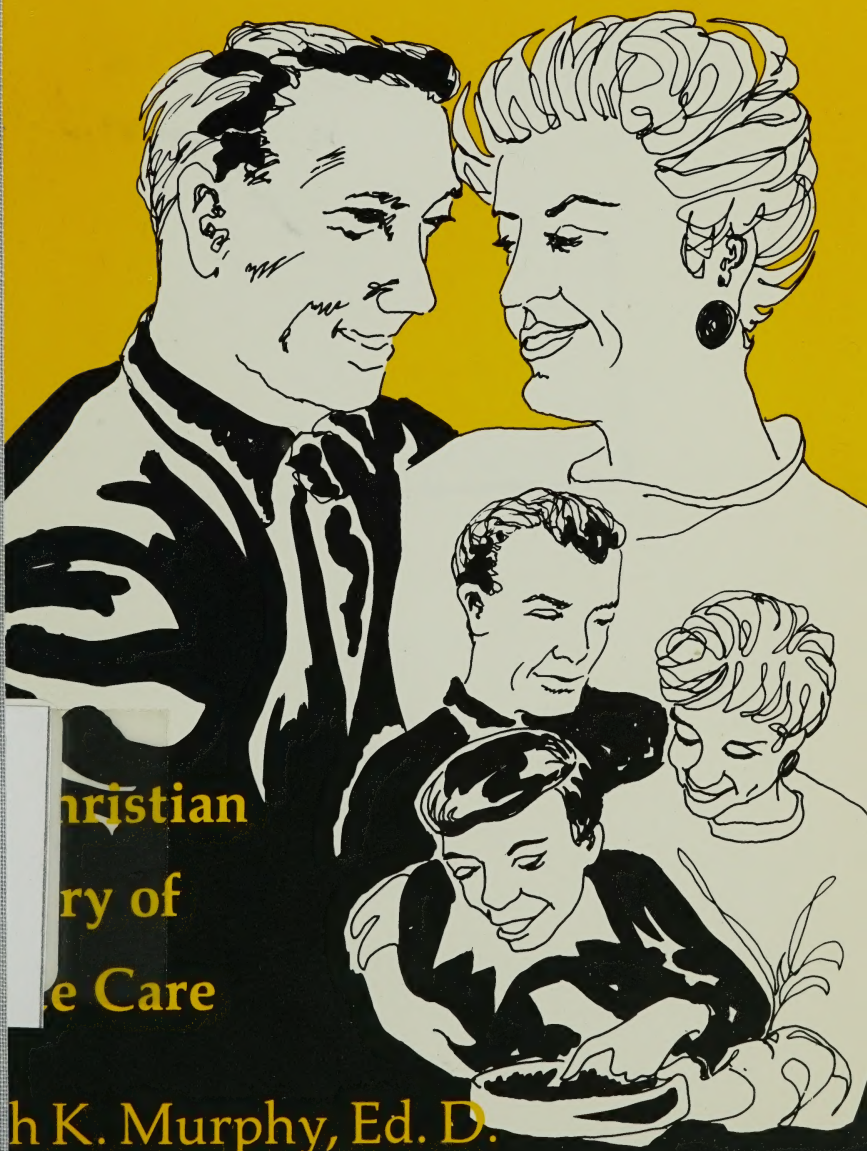

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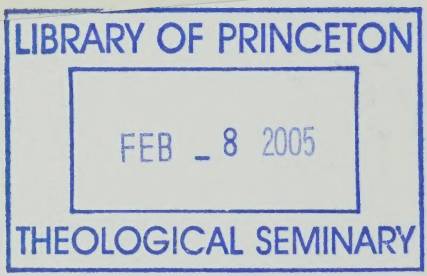

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SHARING CARE

The Christian Ministry of Respite Care

Judith K. Murphy, Ed.D.

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Introduction

MOST persons who care full-time for those who are disabled, frail-elderly, or homebound need relief from their ongoing responsibilities as primary caregivers. Professional caregivers, such as nurses and therapists, have days off, holidays, and vacations. But what of family members who have taken on 24 hour a day, lifetime caregiving? What about the spouse who must care for a partner with a debilitating illness? Or what about the parents who must provide constant care for a child? What about an adult child, already busy with a family, who prefers to care for an aging parent rather than see him or her in a nursing home? The burden of routine medical care, as well as emotional, social, and economic stresses rest heavily on individuals whose dependent loved ones live at home.

If there is no relief from the day-to-day care, the caregiver can become socially isolated, and physically and mentally fatigued. These primary caregivers need relief, a change of pace, a chance to reconnect with their own spiritual resources.

Years ago, when I was a director of a small pre-school for children with disabilities (some people use the words "differently-abled" or "physically challenged"), I became aware of problems parents had in finding babysitters. The parents of twin two-year-old daughters with cerebral palsy had not been out to dinner or a movie since the little girls were born. They took turns caring for the children while one or the other went grocery shopping. They had no relatives in the area who could relieve them from the constant responsibility of feeding, bathing, dressing and playing with their daughters. The children had not yet learned to walk or talk or use the toilet. I asked the mother if she knew a babysitter who might care for them so that she and her husband could spend some time relaxing and renewing their relationship. She was surprised that I should ask and replied "Who would know how to care for my girls? And besides, who would want to? They are such a handful!" Yet she admitted that if she and her husband did not get relief soon, their marriage would suffer.

I had never heard of respite care, but did know of one "seasoned" babysitter in the neighborhood who occasionally opened her home to our children so that parents could go on short trips. She was a godsend to this young couple. From her years of experience with children who had special needs, she knew how to feed, bathe, dress, and play with them. Not only were the parents delighted to leave their daughters with someone qualified and trustworthy, but they also had the chance to strengthen their marital relationship. They arranged for one evening a week of child care, which allowed them a respite and gave them time to spend with each other or with newfound friends.

Before receiving respite, this young couple was socially isolated. They had neither friends nor relatives for emotional support. All too often I receive phone calls from other parents in the same situation. The voices sound tired, strained, and concerned. Unfortunately, the problems of finding quality short-term care are common.

Brothers and sisters also benefit from a respite program. Steven, a senior in high school, had a fourteen-year old brother named David, who was mentally retarded. Steven and his mother attended a panel discussion on what it is like to live with a person who is developmentally disabled. Someone asked Steven what he would have changed, if he could, in growing up with his brother David. He said he would have liked more free time to be with his friends and to participate in school activities. As it was, he cared for David after school, since both his parents worked. His mother added that she would have liked to give more attention to Steven when he was younger. She and her husband had often discussed the conflicts they felt in trying to meet the needs of both of their sons. If respite had been available to this family, Steven would have had more time to socialize and his parents would have felt less guilty about the attention they gave to his younger brother.

These families needed some relief, a break from their responsibilities. There are more, like them, who need respite. Perhaps they are members of your congregation. The chance to see life again with humor, freshness and strength—this is the gift a respite program can offer.

The purpose of this manual is to introduce the idea of respite care as a part of a church's program and mission. This manual will help a congregation through the beginning stages of designing simple respite care programs. It may also be used as a starting point for congregations wishing to involve themselves in more complex programs.

1
What is Respite?

THE word respite (pronounced res-pĭt) is defined in dictionaries as a time of temporary relief from pain, work, or other forms of stress. In this guidebook respite refers specifically to a *period of relief* from the ongoing responsibilities of caring for persons who are disabled, frail-elderly, or homebound. A respite program refers to a service or ministry offering such relief. For example, in addition to providing relief, such temporary care may be useful in a variety of other ways. It can provide a family with a means of coping with both emergencies and everyday responsibilities. But equally important, respite care can give family members an invaluable opportunity for recreation and relaxation, or the chance to pursue an educational or career goal.

Who Receives and Who Gives Respite?

In a broad-based program, those who receive respite would include persons of all ages and with a variety of special needs such as: children and adults with disabilities, persons who are frail-elderly, and individuals who are homebound. A more limited ministry might restrict itself to children with disabilities and their families.

Those who give respite would include any reliable adult or teenager possessing a loving attitude toward the persons who receive their care, among other attributes and skills. People who wish to be respite givers should be trained to become respite providers.

Situations Where Respite Care is Helpful

A *planned vacation* is a time of respite which is arranged in advance and which is longer in duration than a weekend.

Some families seldom or never take vacations because they feel overprotective about their disabled or frail-elderly family member. From the "overprotective" perspective, a primary caregiver may believe that he or she is the only one who can totally meet the needs of a loved one. This person may feel guilty about leaving the family member in someone else's care.

The mother of a 28-year-old woman who is developmentally disabled complained to the local respite coordinator that she would not leave her daughter in someone else's care because it seemed "un-American." As this single parent put it, "I should be responsible and take care of my own." She had not taken a vacation since the birth of her daughter. She was trying to maintain a full-time job as well as care for her daughter, who attended a sheltered workshop during the day. After a friend finally persuaded the mother to take a four-day holiday, she discovered the renewal that time off can bring, and she now rejoices in taking vacations.

Respite care, in the case of *family emergencies*, is usually a result of the temporary absence of a primary caregiver due to circumstances beyond his or her control. A death in the family, an emotional crisis, illness or injury, maternity needs, or an unexpected business trip are all examples of emergencies which can precipitate a request for respite care.

One father of an autistic three-year-old girl was in urgent need of respite care for his daughter after his wife had attempted suicide. Fortunately, the father was helped by an out of town relative. Relief from the demands of care giving can sometimes prevent such desperate situations.

An evening out may refresh family relationships and generally reduce stress. There are times when a short break can help a marriage endure, especially if the partners are caring for a child

with a disability or a frail-elderly parent. We all have *special occasions* such as graduations and weddings that we would not miss for the world! Respite care enables many families to take advantage of these rare and beautiful events.

Sometimes, though, it is the one receiving care who needs a break. It should be recognized that respite is not only needed by family members, but can also be useful to the disabled person who may need time away from the family. He or she, during respite time, is provided with opportunities for learning new skills or making new friends.

One of the most exciting aspects of respite care is the awareness acquired by a caregiver of other perceptions of the loved one in need of care. Their loved one can share life. He or she has given joy to another person. It is equally exciting when care providers break through the stereotypes of disabilities and discover the abilities and personality of their companion.

Teachers in one school system report that the change of environment which respite service offers to special education students is a unique and unexpected source of stimulation. After a weekend of respite care, children are more relaxed in the classroom, new situations are more easily accepted, and friendly interactions among classmates are increased. For some children, a respite situation provides their first opportunity to play with others in their neighborhood. For example, a five-year-old child with cerebral palsy was invited to "come over to play" with another child who lived on the block. The mother of the little girl cried, for it was the first such invitation her daughter had received.

A young man, who is the single parent of a son with a hearing impairment, wanted to take a course at night in a continuing education program. Through his local church he found respite providers wanting experience with persons with hearing impairments.

Research indicates that a change in routine reduces stress. In an article titled "Supporting Families Through Respite Care," the author reports,

> Respite care appears to help families by improving the mental health and social relationships of the parents. Parents used the time allowed them by respite care services primarily to rest and recuperate, meet medical needs, and improve their relationships with other family members. (Cohen, 1982)

When a parent experiences stress, the "other side of the coin" is that the person receiving care may be feeling "stress-full" too. I had a friend who, in his thirties, discovered that he had multiple sclerosis. His aging parents cared for him until he died. I would ask Tony to go swimming every few weeks so that he could get out of the house. This occasional evening out relieved his anxiety about being a

burden to his parents. It is clear that a respite program can reduce the stress of family caregivers *and* of the person to whom care is given.

A unique opportunity exists also for the volunteer to pursue vocational goals by learning about persons who are disabled or frail-elderly. New insights and understandings are gained by both the recipient and the provider of respite care.

There are many more ways in which respite can be provided. If a congregation is willing to initiate and maintain a quality program, the possibilities may be limitless. Churches traditionally have a deeply rooted stewardship and are well-equipped helping communities to respond to those in need of respite service.

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2
Why We Are Called to Give Respite Care

For just as the body is one and has many members, and all the members of the body, though many, are one body, so it is with Christ. For by one Spirit we were all baptized into one body—Jews or Greeks, slaves or free—and all were made to drink of one Spirit. 1 Corinthians 12:12-14

But God has so adjusted the body, giving the greater honor to the inferior part, that there may be no discord in the body, but that the members may have the same care for one another. If one member suffers, all suffer together; if one member is honored, all rejoice together. 1 Corinthians 24b-26

DURING the last twenty years, the churches have been rediscovering the meaning of the Body of Christ. Denominations and congregations have expanded their views, each in their own way, of how we define ourselves as human and as Christian. The concerns of blacks, Latin Americans, women and persons from developing countries have been articulated in theologies calling for the liberation of people from conditions of subservience within the church and within society.

What has become clear is that Christ stands beside the least, the lost and the last. As Paul states in his First Letter to the Corinthians, God has given special honor to the seemingly humbler parts of the Body of Christ. Paul scolds the churches for attempting to cut off humbler parts of the Body as it cuts out people who are seen as less important. "The eye cannot say to the hand, 'I have no need of you.'" It is not good for some parts to be cast in "giver" and others to be cast in "receiver" roles. Rather, to be in ministry, all of the church is needed in mutual ministry to one another.

Increasingly, we are reaching into the Gospels to recover Jesus' words to us. Part of what we have discovered in Luke 14:15-24 is that the heavenly banquet will be made up of those who have been in the margins of our world. What is that banquet to look like? When all the "important people," by earthly standards, made excuses for their failure to attend, Luke tells us that the householder said, "Go out quickly to the streets and lanes of the city, and bring in the poor and maimed and blind and lame" (Luke 14:21b). To be complete, God's heavenly banquet needs all of us to sit down at the table together. If the church is to be a foretaste of that banquet, then we must include those who have been excluded from society's table. Persons with handicapping conditions have been excluded not only from society's table, but also have often been pushed to marginal positions in church life. We must open wide the doors of our churches. We must include *all* people with all their disabilities.

Persons with handicapping conditions have told the churches that they wish to be in ministry with the greater church membership. To answer that need, we must discard the notion of a one-way ministry which serves only the needs of handicapped individuals and their families. Rather, we must recognize the opportunity of providing respite care as mutual ministry.

Mutual ministry will call for some big changes on our part. We must learn how to receive from persons with handicapping conditions as well as how to give to them. The successful respite program is one where every time something is received, something else is also given.

As illustration of mutual ministry, consider Earl and Emma Miner, who agreed to take Larry, a 17-year-old severely mentally

handicapped boy, temporarily into their home. At first Emma thought, "I'll never be able to take care of him for three whole weeks, not with all the special help he needs!" But she gave it a try. Every day she took Larry out of bed and put him on the davenport in the sunny living room. "He loved that," exclaimed Emma. "He ate. He was happy. He was so happy that sometimes it made you feel funny." Emma didn't get any of her quilting done while Larry stayed with them. "It was my own fault. I spent so much time with him," she said. "I don't know where the time went!" She watched for Larry's laugh, the message of his eyes, or the turn of his head to recognize how he felt. "It was so empty around here after he left," said Emma.

Some people in the community expressed their concern about the liability when a young Amish minister and his family also cared for Larry for a time. "What if he rolls off the bed?" people asked. The minister was certain though, that "if you know something is right between you and God, while it still has an impact on you, you don't let what others think influence you." His young children especially loved Larry. The three-year-old son would "kiss and talk to him as any other person." The other child would crawl on the bed at Larry's meal time. The two entertained each other and laughed merrily. "I learned much about giving and receiving," the young minister reflected. "It opened up a whole field of Bible searching on servanthood for me."

The full-time caregivers, those persons who need care, and the respite caregivers are equal parts of a church-based respite program. As programs develop, different gifts will be given and received. There will also be many struggles. Success in respite care will be defined by the degree to which everyone feels as if he or she is a part of this ministry.

Each of us has strengths and weaknesses. God is calling all of us, no matter what our gifts and limitations, to be in ministry. Let respite be an occasion for your congregation to explore mutuality in ministry.

3
How to Organize Respite Care in the Church

CLEARLY defined goals are an invaluable asset to starting a respite care program in the church. The congregation may wish to adopt the following goals which are steps in developing a program. These steps, when implemented, will result in the growth of a program which is responsible to the needs of the persons being served. The steps are:

1. To identify the need for respite services.
2. To help the congregation to become aware of the need for a respite program.
3. To establish an administrative structure.
4. To identify those needing care.
5. To recruit volunteers to be respite providers (see Chapter 4).

6. To train volunteers (see Chapter 4).
7. To match families with volunteers (see Chapter 4).
8. To establish an organizational structure (administrative) to implement the program.
9. To conduct ongoing evaluation of the program.
10. To continue building the respite program (see time line in Appendix C).

Steps four to eight are organizing strategies; steps nine and ten are administrative ones.

Steps two and three go hand-in-hand because some administrative coordination is needed to raise the congregation's awareness. But it is likely that as the congregation becomes aware of the need, you will be able to identify potential members of the advisory council.

Identifying the need

Begin by contacting community agencies and other churches in order to identify programs that may already exist. You might develop a directory of services. Include in the directory the addresses, phone numbers, contact person or people in charge, the kind of service provided, the type of persons who need the service, costs, and any procedures that should be followed for a referral for this particular service. Examples of programs or services you might find in a community are:

- After School (latch key) Programs.
- Home Health Agency, in-Home Respite
- Community Residence or Group Home Respite.
- Foster Home Respite.
- Recreation Program.
- Senior Citizens' Program.
- Drop-off Center.
- Agency Respite Programs, such as The Association for Retarded Citizens or United Cerebral Palsy.
- Respite Center.
- Hospital, or Nursing Facility Respite Care.
- Respite offered by other churches.
- Hospice.

Once you have identified the programs and services that are available, you can then determine any needs still unmet. What kind of respite care is not being provided? Which program should the community expand in order to care for the number of people requiring its service?

Distribute the *Respite Care Program Survey of Need* form to the people

in your congregation. When the forms are returned, you will have an idea of the needs of your congregation. Compare these needs with the community services that are already available. This will indicate the kind of program your church may want to start. Then determine how your program will fit into the total picture of community resources. There is no point in starting an unnecessary program or in duplicating one which does not need reinforcement.

Consider what you can share with other programs. It might be possible to have jointly sponsored training sessions for volunteers. You might agree to set up a community wide referral system, or to provide a transportation cooperative.

Raising the Congregation's Awareness

Ask the people in your congregation who indicated a need for respite care to gather for a discussion. Acquaint them with the concept of respite care and give them the information you have collected about the community services available and the needs expressed in the survey form.

Ask for suggestions about how the respite care program should be organized. What components would they like to see in the program? You might consider such aspects as where and when respite might occur, the length of time respite would be offered, what kinds of volunteers would be needed, what duties the volunteers would have, how they would be trained and by whom. When you have the basic outline of the program, ask for an opportunity to present a proposal to the governing body of your congregation. Present the facts about the programs available and the needs of the community and the congregation. Outline the program you would like to set up and the ways you would cooperate with other church or community groups. When you have the support of the governing body discuss the possibilities for making the whole congregation aware of the need for a respite care program. Also ask the people who need respite to help organize events which will alert the congregation to the needs and plans for respite care. Information about respite care should be presented to elicit the backing of the congregation and to encourage volunteers.

Establishing an Administrative Structure

A common structure is one which has an administrative council and a coordinator. The administrative council acts in much the same capacity as a board of directors. It is a responsible decision-making body that establishes policies and guidelines of the program, oversees the program's operations, and supports and supervises the coordinator. The coordinator is accountable to the administrative

council. The administrative council may guide the development of the program, do public relations work and evaluate the program. The administrative council should include those who participate in the program by giving or receiving care. It may also include professionals in the field such as nurses, special education teachers, psychologists, social workers, lawyers, physicians, or other interested people. If your respite program is implemented through a coalition of churches or in partnership with a community program, representatives from each church or community partner should serve on the council. The administrative council should have a balance of people with knowledge and expertise in care of the persons with handicapping conditions or in the area of gerontology, as well as people with enough time, energy, and organizational ability to devote to the program.

In order to recruit the administrative council you might have a series of pot luck dinners or meetings which essentially "sell" the idea of respite care to the persons attending. These dinners or meetings can take place after the initial introduction of the respite program to the congregation. Invite as many persons as possible to the series. Target a particular segment of the congregation to attend each gathering so that you have contacted every member by the end of the series. This part of the process may take weeks or months, but the efforts wil eventually bear fruit and enable the program to emerge. From each gathering you will recruit a certain number of individuals to sit on the advisory council that will build the respite program.

While the administrative council has broad responsibilities, the respite coordinator manages the week to week supervision of the program. The coordinator does a variety of jobs, among them:

1. Assessing the need for respite.
2. Finding families and providers.
3. Coordinating training workshops and continuing education sessions.
4. Matching families with providers.
5. Arranging individual respite instances (this applies only to some models; see Chapter 5).
6. Following up on family and provider satisfaction.
7. Documenting how much respite is provided, when, and by whom.
8. Calling administrative council meetings.

There are certain "tools" which are essential in assisting the coordinator with the building of the program. A desk and a place to keep information about families and volunteers is needed, as is access to a telephone and office supplies.

Beyond these tangible tools, the coordinator will need help from the pastor and the administrative council in at least five areas: launching a public awareness campaign, finding families and volunteers, conducting training workshops, obtaining funds for the respite coordinator's salary (if he or she is to be a paid staff person), and program evaluation.

Administrative council members who actively participate in building the respite system are an invaluable resource to the respite coordinator. With the cooperative efforts of pastor, coordinator, and administrative council, the following tasks can be successfully completed:

- A public awareness campaign.
- Program brochures.
- Public service announcements.
- Slide presentations.
- Newspaper feature articles.
- Presentations on radio and television talk shows.
- Public speaking engagements.

Basic Policy

Once an administrative council is established and a coordinator selected, a few basic questions need to be answered. The program must be designed to respond to the needs of three groups: the families of the persons needing care, the individuals needing care, and the respite providers. If the following questions are answered, the coordinator, pastor, and administrative council will be well on the way to creating respite program policies.

1. Which respite model(s) do we need to initiate? (See Chapter 5 for types of models.)
2. Whom do we want to serve (e.g., families of children and adults with disabilities, frail-elderly persons, and/or homebound persons)?
3. Where do we need to serve them (e.g., in family's home, in provider's home, in church, in community center, in agency)?
4. How extensive a training program do we need for providers? How much help do we need from families and how much from professionals?
5. When do we need to offer respite care service (e.g., hourly, daily, overnight, weekend, weekly)?
6. What are the acceptance criteria for those needing service and those providing service?
7. What are the capabilities we will expect and what limitations will we allow of respite caregivers?

8. What will we do if a request is made for care but no provider is available?
9. What are the responsibilities of the administrative council, coordinator, user, and provider?
10. What is the policy on confidential information?
11. How will the church be responsive to the needs of users and providers, recognizing that these needs continually change?
12. What is the program evaluation procedure?

Before the program begins, the coordinator or the administrative council should consult with an attorney about liability and secure the necessary insurance to cover any accidents or problems.

Evaluation of the Program

A process for yearly review and evaluation of the respite program should be developed jointly by the pastor, respite coordinator, and administrative council. From the beginning, a respite organization motivated by the need to respond in loving awareness will be able to determine the capabilities and limitations within the ongoing program.

Churches considering a respite service need "permission" to not be all things to all people, but rather to provide a quality of care motivated by a calling to service. An evaluation question that can be asked throughout the planning and implementation of a respite service is, "Does this decision have as its motivation the desire to respond to the call to be Christ's disciple in today's world?"

From a programmatic standpoint, an ongoing evaluation of user and provider satisfaction can be done with the family and provider response cards (see Appendix A for samples). Personal interviews or telephone surveys by the respite coordinator are additional evaluation sources.

It is essential to discover why families are or are not using the service. What are the changing needs of families and persons receiving care? Are there problems with transportation? With what frequency are respite providers available when primary caregivers need respite? Why do providers participate or drop out? What are the training needs of providers? Answering these questions will give hints as to how effective the program actually is.

The coordinator and administrative council should be mindful of the following vital elements which may enhance the success of a respite program.

1. Service which is motivated by loving concern.
2. Continual involvement of families and persons receiving care in program planning and evaluation.

3. Ongoing effort to find volunteers.
4. Training of volunteers.
5. Using the services of respite volunteers.
6. "Paying" volunteers in terms of meaningful experiences, personal accomplishments, discovery and recognition.
7. A respite coordinator who takes care of the week to week demands of the program.
8. Building a respite service which is responsive to the changing resources and needs of families and
9. A stable funding source to cover the respite coordinator's salary (if the position is salaried) and training costs.

4
Finding, Training, and Matching

Finding Families

THE simplest way to find families is to hand out the *Respite Program Survey* (see Appendix A) at Sunday services and to send the survey to agencies in the community which serve disabled individuals or the frail-elderly.

Families who need to receive respite care, and host families who are able to provide it will be discovered in the beginning phase of the program at small group dinners or meetings about respite care. As the program builds, these families will "sell" others on the benefits of getting short periods of relief. Newcomers can also be included in

program planning and training workshops. Encourage families who will be using the service to bring potential providers with them to training workshops.

Keeping Families Involved

Occasional informal meetings and telephone follow-ups with families will provide the respite coordinator and administrative council with a sense of how satisfied respite families are with the program. A family member is more likely to feel at ease telling about their respite provider's quality of caring at an informal gathering than at a formal meeting. These gatherings will also provide an opportunity for the coordinator to learn about the families' ideas on additional training needs of volunteers.

Discovering how families and persons receiving care feel about the training of respite providers is an essential ingredient in program evaluation. If persons receiving care and family members are not pleased with the service provided, they will not continue to use the respite system. If the volunteers are not called upon to serve, they may drop out of the program. Early identification of "trouble spots" and their remediation can prevent dissatisfaction on the part of both recipients and volunteers.

Finding Volunteers

Volunteer respite providers can be recruited from a variety of places. A good bit of creativity and hard work may be needed to uncover the wealth of volunteer resources.

Look for potential providers among high school and college students, early retirement persons who want to stay active, professionals, business persons, and church members who have time to volunteer. Providing respite care allows a high school or college student the opportunity to experience what it is like to be with a person with special needs. Some young caregivers have made career choices based on these experiences. To recruit students, contact instructors in high schools, universities, or community colleges, and ask to do a presentation about the program. Classes in health, gerontology, occupational therapy, physical therapy, art therapy, nursing, psychology, special education, family studies, home economics, adaptive physical education, and social work can be targeted. Some instructors give class credit to students who become providers.

Nurses, special education teachers, and art therapists are among those who may be willing to be with persons who need specialized

respite care. They can be recruited from community service organizations.

Professionals in many fields can be located through professional organizations and places of employment. Many business persons, ordinarily not associated with human services during the work week, would gladly contribute time on weekends, if only they were asked.

In terms of a continuous volunteer-finding strategy, a public awareness campaign can be conducted by the advisory council, respite coordinator, and families. The first step is to develop written material which describes the program and the need for volunteers. Such a brochure or flyer can be distributed during public speaking engagements and included in correspondence. (See Appendix A for samples.) Some banks, telephone or utility companies allow brochures to be enclosed in statements or billings.

Additional contacts can be made by letters or telephone, or through newspapers, radio or television. Newspapers may be used in a number of ways. For instance, help-wanted ads can be placed in the classified section of any paper. Do a feature article on a family who needs relief and give information on the dates of training workshops. Do radio and TV public service announcements of upcoming volunteer training workshops. Radio talk shows with respite users or volunteers who were early recruits are also effective. Contact a TV station and ask the news team to do a special events interview with parents and volunteers at some of the training sessions.

Once a respite program is underway, the administrative council may want to develop a slide show to be used in outreach to volunteers and families. You may want to have two different slide shows—one to recruit volunteers and one to find families. Whatever approach you take, remember the old saying that "a picture is worth a thousand words."

Another method of finding volunteers is to ask existing volunteers to bring a friend to a training session. Families can also be resources of care providers. Many have grandparents, aunts, uncles, and neighbors who are excellent providers. These volunteers from extended families and neighborhoods may, in fact, be among the most steady providers over the course of many months and years.

Keeping Volunteers Involved

In the program building process, every volunteer participates in a screening interview, which gives the respite coordinator a feeling for how reliable a volunteer is in making common-sense judgments.

Questions about an individual's attitudes toward persons who are disabled or frail-elderly may be addressed at this time. A completed *Respite Provider Application* form (see Appendix A) gives additional information about a volunteer's availability, interests, and preferences concerning the respite care site and persons to serve.

Involve volunteers in training workshops as soon as possible. This will provide an immediate sense of being part of the program. After a training workshop, the respite coordinator should arrange for each volunteer prior to actually beginning service, to have at least two meetings with the one or two families he or she will be serving. These meetings should help to "break the ice," as many families are shy about calling their provider, even if they have been introduced at a training workshop. Valuable information about the care needs of the person being served will be shared. After these first meetings or home visits, the family and volunteers should trust each other enough to make their own arrangements for respite care.

It is important, however, to remain in touch with volunteers and there are various ways of doing this. One approach is to ask regularly what volunteers' needs are. More ideas on leisure time and recreational activities is a common request. Or some providers may want more "hands-on" experiences. Such experiences can be arranged in cooperation with special education classes, state facilities, private schools, or nursing homes.

While educational needs of volunteers are one thing, emotional needs are quite another. Opportunities for expressing appreciation for volunteers' work should be built into the respite system. For example,

1. Arrange a volunteer recognition week for families to do something special, either collectively or individually, for their care provider.
2. Plan an awards luncheon at which every volunteer receives an award.
3. Have an appreciation cookout where volunteers and families play and eat together and the only thing a volunteer has to do is show up!

Most volunteers will continue to be volunteers if they have a trusting relationship with their families, if their educational and emotional needs are being met, and if they feel they are making a significant contribution. They want to serve as Christ's disciples and to share Christ's love with others. But they cannot share unless families and persons receiving care call upon them to do so. One of the main reasons volunteers leave is because they are underutilized. It is crucial to involve volunteers immediately. It is equally crucial to keep them involved.

Developing a Volunteer Network

Building bonds of common interest and friendship among respite caregivers is the key to developing a cohesive volunteer support network. Regular social events, arranged just for volunteers, provide a feeling of community.

Many volunteers desire to identify with a group which is dedicated to spiritual and practical service to persons with special needs and their families. Social events such as pot luck dinners, coffees or parties allow respite caregivers to share experiences. Such gatherings provide encouragement to new providers who may feel anxious about assisting a frail-elderly or disabled person. On the other hand, a "seasoned" volunteer may genuinely benefit from the fresh, energetic approach of a newer member of the group.

Volunteer network support gatherings also provide additional opportunity for program evaluation. Answers to questions such as these are vital: Are families using your services? If not, why not? Are you pleased with the family or families with whom you've been matched? What improvements can be made in the overall program? What are your training needs?

Matching Families with Providers

Families need to trust their provider. Guilt about taking time to be away from a dependent loved one *can* be relieved, but only if family members are willing to take a leap of faith, knowing that their special one is in good hands.

Depending on the respite model(s) your congregation chooses, the respite coordinator will make matches based on geographical location, hours volunteers are available, and the respite provider's ability to handle a family's special needs. Implications of the match for both the family and the person receiving care should be considered. When the relationship between the provider and the person receiving care is comfortable for both, a good match has been made. As God gives each of us life every day, this gift of life is filled with unknown potential. The person receiving care has the potential to touch the care provider in ways never expected.

Home Visits

The respite coordinator and the care provider will make two home visits to the person receiving care and his or her family. The purpose of the first home visit is to introduce the family to the care provider and to discuss responsibilities and expectations. Information about the needs of the person receiving care should be reviewed, and questions regarding emergency contacts must be

answered. Some respite models (e.g. Extend-A-Family) have written agreements which are signed during the first visit to the family's home.

A second type of home visit takes place in the provider's home, if this is to be a location where respite care is given. Family member(s), person receiving care, and respite coordinator visit the provider's home in order to familiarize the receiver of care with what will be his or her new environment. The provider's home should accommodate the person receiving care. If, for example, the person receiving care is in a wheelchair, the home must be free of architectural barriers such as stairs. If the person receiving care has allergies, the home should be clean and uncluttered, as dust may be irritating. Ask the volunteer to provide the name of his or her homeowner's or tenant's insurance company. Liability coverage regarding personal injury and/or damage to property is usually provided in homeowner's or renter's insurance policies.

Responsibilities of Families

The respite coordinator may provide a checklist for families receiving respite care. The following items could be included:

1. Complete the respite application packet which includes the *Application Form, Permission to Get Emergency Medical Help, Summary of Personal Information and Basic Routines,* and *Statement of Non-Liability.* (See Appendix A for forms.)
2. Leave information about where to reach the respite coordinator on the *Emergency Addresses and Telephone Numbers* form. It is important that the respite volunteer have this information.
3. Check prescription medications to be sure that labels are readable and correct. Instruct the respite provider carefully as to how to administer the medication.
4. Provide adequate food, clothing, and spending money for the person receiving care.
5. Allow enough time to update the respite provider on any changes in basic routines of the person receiving care.
6. Fill out and return the *Family Response Card* to the respite coordinator. This gives the coordinator an indication of your satisfaction with the service.
7. Please be considerate. Give the respite provider as much notice as possible before respite service is required. Also, return at the time you say you will return.
8. Inform the respite coordinator of any changes in your phone number or address.
9. If brothers or sisters of a child with a disability are also to be cared for, please let the volunteer know. Be sure that both

the provider and the other children know this.
10. Keep the respite coordinator informed as to when your family received respite and from whom.

Responsibilities of Respite Providers

A checklist for providers should include the following:

1. Provide information about the preferences and basic routines of the person receiving care. The family or respite coordinator will make copies of the following forms available to you: *Summary of Personal Information and Basic Routines, Permission to Get Emergency Medical Help, Permission to Give Medication* (if the person requires it), and *Emergency Addresses and Telephone Numbers.*
2. Ask the family to instruct you in administering medication. Read the label carefully before you give the medication to the person for whom you are caring.
3. Use your best judgment and respite training skills in working with the person in your care.
4. Respect the privacy of the family. Personal information about the family or person receiving care is to be kept confidential.
5. If you have questions about how to care for an individual, ask family members or the respite coordinator. The quality of care you give will be enhanced if you understand each person with whom you work.
6. Report to the family any unusual events that occur during your time of service.
7. Be considerate. If you have to cancel, do so as soon as possible so the family can get another volunteer.
8. If you give care in a family's home, be on time. Before the first respite instance, be sure to become familiar with the home.
9. Fill out and return the *Provider Response Card* to the respite coordinator.
10. Inform the respite coordinator about changes in your availability, phone number, or address.

Training Volunteer Respite Providers

Three respite models (volunteer respite provider, sitter/companion, and drop-in center) include provider training workshops and continuing education as a major component. Parents or other family members directly train providers in the remaining respite models (Extend-A-Family, Respite Care Co-op, and One-to-One Respite Exchange).

Needs of the persons receiving care must be identified before the training workshop(s) so they can be shared with providers. Care needs are specified by the primary caregiver in the *Summary of Personal Information and Basic Routines* form in Appendix A. A training curriculum responding to these needs is developed or chosen by the respite coordinator from a wide variety of existing training materials (see section on "Provider Training Materials" in the bibiliography of this guidebook).

In a training program, the following topics offer a well-rounded curricular approach:

1. Needs and feelings of the family seeking respite service.
2. Attitudes of providers toward persons with disabilities and the frail-elderly.
3. An overview of various types of disabilities.
4. Communication.
5. Positioning, lifting, and transferring.
6. Dressing (including putting on and taking off braces), eating, bathing, and toileting.
7. Basic emergency and health care by the non-professional.
8. Leisure and play activities.
9. Following instructions about medication.
10. Special diets and snacks and/or meal and snack planning.

Training may be done by parents or other knowledgeable persons, such as a physician, psychologist, special educator, emergency medical technician, nurse, social worker, physical education teacher, occupational therapist, art therapist, music therapist, speech therapist, physical therapist, or respite coordinator. If the decision is made to include first aid instruction, contact the American Red Cross.

Ask presenters—those conducting the training—to use a teaching style which combines experiences with lectures. For example, conduct small group discussions and hands-on demonstrations. Distribute practice materials and present films as well as lectures.

The specific time and location of training workshops should be arranged at the convenience of families and volunteers. The total length of a training program may vary. A minimum of ten hours is essential. A sample training program appears in Appendix B. The sample training program can be expanded depending on the needs in each locale. An extended model *Companion/Respite Caregiver Project Training Schedule* is also included in Appendix B.

The importance of involving parents and other household members in the training process cannot be overstressed. Through their involvement, families will gain confidence in the program. Encourage families to come to training workshops. They may be

excellent presenters. When possible, include persons receiving care in the planning process. Primary caregivers and persons receiving care have an abundance of knowledge about the day to day needs of a dependent person.

After completing their training workshops, some volunteers may want or need additional experiences. Short-term learning opportunities can be arranged through nursing homes, schools, group homes, hospital therapy departments, and special education classes. Continuing education meetings planned by the respite coordinator on topics requested by volunteers is another means of extending practical experience.

5
Respite Models

LOCAL congregations have a variety of existing respite models from which to choose. Any one or combination of models may be implemented. Creative adaptation of models to local needs and circumstances is encouraged.

In this chapter, a brief summary of models is presented. Resources for more information on a particular model are listed at the end of each summary.

Model: Volunteer Respite Provider

ADMINISTRATION

The respite coordinator recruits both those receiving respite and volunteer providers. Each respite is arranged by the coordinator.

PROGRAM

Volunteer respite providers furnish respite care in their own homes, the home of the family receiving respite, or at a drop-in center. The procedure for arranging respite is as follows:

1. A primary caregiver's request for respite is taken by the respite coordinator.
2. The coordinator contacts trained volunteer providers to determine who is available at the time respite is needed.
3. If the volunteer is new to the family, home visits are arranged to provide introductions and initial acquaintance.
4. If respite care is planned in the provider's home, an orientation to that environment is arranged for the family and person receiving care.
5. After the respite is completed, both family and provider are asked for feedback regarding their satisfaction with the service and/or problems encountered.

The following forms and agreements are filled out by the primary caregiver (PC) or the volunteer respite provider (RP) (See Appendix A for sample forms):

1. Application Form (PC).
2. Respite Provider Application (RP).
3. Permission to Get Emergency Medical Help (PC).
4. Permission to Give Medication (PC).
5. Summary of Personal Information and Basic Routines (PC).
6. Emergency Addresses and Telephone Numbers (PC).
7. Statement of Non-Liability (PC).
8. Family Response Card (PC).
9. Provider Response Card (RP).

TRAINING

The respite coordinator sets up training workshops and continuing education sessions for volunteer respite providers. Families are included in training workshops whenever possible.

RESOURCES

1. For more information, send for: "Respite Care: A How To Manual" by C. Carron. Available from: Cary Carron, Archdiocese of Denver, CARES, 2141 South Zenobia Street, Denver, Colorado 80219

2. See the *Provider Training Materials* section of the bibliography in this guidebook for specific information on content of respite provider training workshops.

Model: Sitter/Companion

ADMINISTRATION

This model is similar to the volunteer respite provider model except that the provider (sitter/companion) is paid a modest fee for service. The respite coordinator administers the program. In a structured approach, the coordinator arranges for each period of respite. In a less structured approach, the coordinator compiles a list of qualified sitter/companions and supplies it to families who will then make their own arrangements for care and payment.

PROGRAM

The sitter/companion provides respite in the family's own home or in a sitter/companion's home. Families who can pay for planned respite on a regular basis are good candidates for this model.

A "sitter" is for a child. A "companion" is for an adult. The "companion" is also referred to as a "friend-companion."

TRAINING

Sitter/companions are recruited, trained, and placed on a list of qualified providers by the respite coordinator. The content of training sessions is similar to that of the volunteer provider model.

FEE

Sitter/companions are paid a modest fee by families. The fee may be negotiated between families and providers, or a standard fee may be established within program policy. In some programs, the charge is less for basic care and more for the complex care required where there are medical or behavioral problems.

RESOURCES

1. A training manual is available from: Respite Coordinator, San Diego County Association for the Retarded, Sitter Service for the Handicapped, 3035 G Street, San Diego, California 92102.
2. A program manual is available from: Meyer Children's Rehabilitation Institute, University of Nebraska Medical Center, 444 South 44th Street, Omaha, Nebraska 68105.
3. *Family Support Services: Respite, Sitter-in-Home Program Handbook* is available from: Support and Licensing Manager, Arizona Department of Economic Security, Division of Developmental Disabilities and Mental Retardation Services, 3727 East McGowell, Phoenix, Arizona 85006.
4. Also see this guidebook's bibliography.

Model: Host Family (Extend-A-Family)

ADMINISTRATION

The respite coordinator organizes this program with parents, according to guidelines from "Extend-A-Family" (see below).

PROGRAM

The Extend-A-Family concept originated in Toronto, Canada. The essential component of the program is one or more host families who are willing to extend hospitality to families with a disabled child. The model could be adapted to include frail-elderly persons who are able to leave their own home for a visit with a host family.

The respite coordinator finds both natural—receivers of services—and host families who want to participate. Families are screened and a one-to-one match is made between a natural family and a host family. Families receiving service and host families make their own arrangements. Success of this program depends to a great degree on an appropriate match.

A written agreement for Extend-A-Family care is signed by both the natural and host families. The agreement includes the host family's authorization to seek medical treatment and a statement regarding liability.

TRAINING

There is no formal training, but the natural family may choose to communicate information about care of their relative to the host family.

RESOURCES

1. For complete guidelines on how to organize a program, write for a free single copy of *Extend-A-Family* (1976) by A. Brightman. It is available from: Director, Extend-A-Family, 35 Lytton, Toronto, Ontario M4T 2G1 Canada.
2. Also see this guidebook's bibliography.

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Model: Respite Care Co-Op Program

ADMINISTRATION

The Respite Care Co-Op Program enables parents of developmentally disabled persons to provide each other with respite care and mutual support. A sponsor agency supports the program and provides a professional program coordinator. The coordinator needs to

have skills in the areas of working with groups, program development and innovation, and working with families.

The *parent-professional team* is the base and strength of the program. Teamwork begins with a steering committee of parents and coordinator who together develop care exchange rules and program policies and procedures. A Care Co-Op Program may sponsor any number of Care Co-Op groups, each with its own set of officers—chairperson, care manager, training workshop manager, and secretary. The Co-Op chairperson serves on the steering committee, which continues in a policy-making and advisory capacity. The particular skills of parents and coordinator combined are essential to success in both start-up and continuation of this program. Neither parents nor a professional can begin or operate a Co-Op Program alone.

PROGRAM

This model was developed for families with disabled children and youth. This Co-Op model has since been adapted to serve caregivers of frail-elderly persons. Further use with other caregivers is possible. The Care Co-Op Program is professionally-facilitated parent self-help. Families help families through exchange of respite care and mutual support, which most members find of equal value. No money is exchanged. The care manager arranges for care and records care hours given and received. As needed, the coordinator guides and supports the processes of care exchange, mutual support, and problem solving. As this program is a preventive use of respite care rather than a crisis program, it is suitable for many but not for all families needing respite.

TRAINING

With the coordinator's guidance and organization, parents train each other to care for their disabled persons. A folder containing extensive care information accompanies each child who receives care. Parents must be trained to deal with each child they will care for.

RESOURCES

1. Lindsay/Ferguson Associates will provide:
   a. A tape-guidebook kit: "Introducing the Respite Care Co-Op Program."
   b. Training and technical assistance in starting and operating a Care Co-Op Program.
   Both are available from: Lindsay/Ferguson Associates, 2324 West Main Street, Kalamazoo, Michigan 49007.
2. Also see this guidebook's bibliography.

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Model: One-to-One Family Respite Exchange

ADMINISTRATION

Two families wishing to exchange respite care are recruited and matched by the respite coordinator. The families make their own arrangements for respite service to each other.

PROGRAM

This model approaches the form of a "mini-co-op" in which two families instead of five or more agree to exchange hours or days of care. Each primary caregiver fills out forms such as: *Permission to Get Emergency Medical Help, Permission to Give Medication, Emergency Addresses and Telephone Numbers,* and a *Statement of Non-Liability.* (See Appendix A for sample forms.) Each family and the respite coordinator retain copies.

TRAINING

Provider training is done together by the two families. They exchange the "Summary of Personal Information and Basic Routines" form (see Appendix A), and regularly update one another on changes.

RESOURCES

See this guidebook's bibliography.

Model: Drop-in Center

ADMINISTRATION

The respite coordinator recruits participating families and monitors the overall program. One or more other persons supervise activities at the center.

PROGRAM

Families take their family member to a group care or recreation setting for a short period of time. The location of a drop-in center may be a school, church, community center, private home, or agency. Hours when respite is offered to "guests" are determined according to family needs and the availability of people to supervise activities. Drop-in centers can be developed for children, teenagers or adults who are disabled. The type of equipment and games used at a center will depend on the age group it serves and the abilities of the guests. The respite coordinator makes sure there is insurance coverage for personal injury or damage to property. Space for the drop-in center is donated or rented.

TRAINING

Individuals who supervise activities usually have had experience in working with disabled persons or have completed a respite provider training workshop. The center might also draw on the services of recreation leaders and have them attend the training workshops.

RESOURCES

1. For further information, read:
   "Respite Care: A Plan for Volunteer Action" by T. Gould in *New World Outlook*. January 1983, 34-36. United Methodist Church, General Board of Global Ministries, Room 1330, 475 Riverside Drive, New York, New York 10115.
2. Also see this guidebook's bibliography.

Model: Information and Referral Network

ADMINISTRATION

The respite coordinator is a reference point for information on all respite programs in the local area. When a request for respite is received, the coordinator refers the primary caregiver to a program which will best serve his or her needs and the needs of the person receiving care.

PROGRAM

Neighboring congregations may have respite programs which would accept participation from those outside their membership. Agencies such as Easter Seals, Association for Retarded Citizens, United Cerebral Palsy, YMCA, and YWCA sometimes have respite or recreation programs to which families can be referred. Administrators of some community residences and group homes keep one or more beds open for "guests" whose families need relief. A guest may stay for a few hours or several days, depending on the availability of space. Home health agencies may offer emergency or planned respite via the home health aide/homemaker program. Though few exist, respite care residences provide professional round-the-clock care.

The respite coordinator keeps a file on each program to which referrals may be made. The file includes information such as the following:

1. The name of contact person.
2. Those persons who are eligible to receive respite.
3. The type of respite care provided.
4. Duration of care provided (hourly, daily, overnight, weekends, weekly).

5. Where respite is to be provided (home of family, home of provider, after school drop-in center, evening care center, etc.).
6. The fee required for the service.

When a primary caregiver requests respite care, the coordinator refers him or her to an appropriate program. The coordinator makes a follow up contact to determine if the family was satisfied with the quality of service.

Much networking and public relations work with local groups is required for this model to be successful.

TRAINING

None.

RESOURCES

1. For more information, read:
   "A Coalition Approach to Respite Care" (1977) by C. Moore; available from: Montgomery County (Maryland) Association for Retarded Citizens, Family and Community Services, 11212 Norris Drive, Silver Spring, Maryland 20902; or from Eric Document Reproduction Service, P.O. Box 190, Arlington, Virginia 22210 (Order number ED-145613).
2. "Family Resource Services and Support Systems for Families with Handicapped Children" (1979), by B. Loop and W. Hitzing; available from: Meyer Children's Rehabilitation Institute, University of Nebraska Medical Center, 444 South 44th Street, Omaha, Nebraska 68105.
3. Also see this guidebook's bibliography.

Appendix A
Sample Forms

Respite Program Survey of Need

Respite is defined as a period of relief from the ongoing responsibilities of caring for a dependent loved one. A respite program provides short-term care.

1. Which best describes your dependent loved one?

   ____ a child with a disability ____ an adult with a disability
   ____ a person who is frail-elderly

2. Do you need someone to care periodically for your child or relative?

   ____ yes ____ no

3. When you need someone to care for your child or relative, who does it?

   ____ immediate family member ____ friend ____ sitter

   ____ foster care home ____ relatives ____ home health

   aide ____ residential facility staff

4. In what type of situation would you use a respite program?

   ____ planned break from ongoing care ____ emergency

   ____ both

5. When would you most need or use a respite program?

   ____ evenings ____ weekdays ____ overnight ____ holidays

   ____ vacations

6. How often and for how long each month would you need respite?
   Estimated period of time: _____

7. Where would you like respite to take place?

   ____ in my home ____ in someone else's home

   ____ in a care center

8. Which of the following types of respite services would you like to know more about?

   ____ volunteer respite provider

   ____ sitter/companion

   ____ care by a host family

   ____ a family co-op

____ shared exchange of time with one other family

____ a drop-in or care center

9. Are you able to provide transportation if you participate in a program outside your home: ____ yes ____ no

Name: _____ Phone: _____

Address: _____

_____

Respite Program

APPLICATION FORM

Date: _____

Name: _____ Phone: Home _____

Address: _____ Work _____

_____ Zip: _____

Name of person to receive care: _____

Reason(s) for respite request (e.g., emergency, planned vacation, an evening out, shopping, recreation, etc.):

_____

_____

I would like respite care to be given

____ in my home ____ in provider's home ____ in care center (drop-in center)

I need respite to be provided on a regular basis. ____ yes ____ no

If yes, when and how often? _____

I learned about this program from: _____

I have homeowner's or tenant's insurance ____ yes ____ no

Type of medical insurance: _____

Policy Number: _____

Respite Program

RESPITE PROVIDER APPLICATION

Date: _____

Name: _____ Phone: Home _____

Address: _____ Work _____

_____ Zip: _____

1. When are you available?

   ____ morning ____ afternoon ____ night

2. Would you like to care for:

   ____ a child ____ an adult ____ no preference

   ____ a female ____ a male ____ no preference

3. Do you prefer to care for a person

   ____ in your own home ____ in the person's own home

   ____ in a drop-in or care center ____ no preference

4. Do you speak a language other than English? ____ yes ____ no

5. If yes, which language? _____

6. Do you know sign language? ____ yes ____ no

7. What are some of your interests and/or hobbies? _____

_____

8. Have you ever cared for a disabled, frail-elderly, or homebound person?

   ____ yes ____ no

9. If yes, please tell briefly about your experience. _____

_____

_____

10. Do you have training that will help you be a respite care provider?

    ____ yes ____ no

11. If yes, please describe. _____

12. Do you have your own transportation? ____ yes ____ no

13. List two references other than relatives.

    a. Name: _____

    Address: _____

    Phone: _____

    b. Name: _____

    Address: _____

    Phone: _____

14. Why do you want to be a respite volunteer?

15. What do you expect to gain from being a respite provider?

Respite Program

PERMISSION TO GET EMERGENCY MEDICAL HELP

I (we) authorize the respite provider, _____ to get emergency
(name)
medical treatment, when necessary, for the following child (children) and/or adult(s): _____
(name or names)

Date: _____

_____
Signature(s) of Relative(s)

PERMISSION TO GIVE MEDICATION

I (we) give permission to the respite provider, _____
(name)
to administer medication according to the written instructions below.

_____

_____

Date: _____

_____
Signature(s) of Relative(s)

Adapted from Judith Murphy, *Home Care of Handicapped Children: A Guide.* (Lyons, Colorado: Carol L. Lutey Publishing, 1982.)

Respite Program

SUMMARY OF PERSONAL INFORMATION AND BASIC ROUTINES

1. Name: _____ Date of Birth: _____
   (person receiving care)
2. Disability (if person is disabled): _____
3. Seizure: Type _____ Frequency _____

   Comments: _____
4. Will the respite provider be expected to give medication?
   ____ yes ____ no

   If yes, please fill out "Permission to Give Medication Form."
5. Allergies: _____
6. Medical problems: _____
7. Assistance with equipment (e.g., person needs help with braces, wheelchair, colostomy, catheter, tube feeding, etc.): _____

   _____
8. A typical daily menu:

   Breakfast Lunch Dinner

   _____

   _____

   _____
9. Snacks: _____
10. Ability to eat and drink independently: _____

    _____
11. Sleeping routine: _____

    _____
12. Toileting (e.g., is the child toilet-trained? Are there special instructions?):

    _____

    _____

    _____

    _____

13. Ability to dress independently (i.e., can person put on shoes, tie shoe-strings, button, zip, snap, put on pants, put on T-shirt, etc.?):

_____

14. What does the person like to do in his or her leisure time?

_____

15. Behavioral characteristics (i.e., are there unique behavioral problems?):

_____

16. If yes, how are behavioral problems handled?

_____

17. Is there anything else you want the respite provider to know?

_____

_____

18. The person prefers care to be given by:

____ female ____ male ____ it doesn't matter

Adapted from Judith Murphy , *Home Care of Handicapped Children: A Guide.* (Lyons, Colorado: Carol L. Lutey Publishing, 1982.)

Respite Program

EMERGENCY ADDRESSES AND TELEPHONE NUMBERS

Name of physician: _____

Office address: _____

Office telephone: _____

Home telephone: _____

Address of preferred hospital: _____

Telephone of hospital: _____

Other telephone numbers: _____ Police

_____ Fire Department

_____ Poison Control Center

_____ Taxi

Address where relative(s) can be reached: _____

_____

Telephone where relative(s) can be reached: _____

If relative(s) cannot be reached, contact:

Name: _____

Address: _____

Telephone: _____

When calling the doctor in an emergency:

1. Give your name and the person's name.
2. Immediately give your telephone number in case you get cut off.
3. Mention the reason for calling (e.g., cut on head due to fall) and symptoms.

Adapted from Judith Murphy, *Home Care of Handicapped Children: A Guide.* (Lyons, Colorado: Carol L. Lutey Publishing, 1982.)

Respite Program

STATEMENT OF NON-LIABILITY(S)

I (we), _____ (name of primary caregiver), the undersigned relative(s) of _____ (name of person receiving care), agree not to hold the respite provider, _____ (name of provider), liable for any illness or accidental injury to my (our) relative while he/she is in the care of the provider.(name of primary caregiver) (name of person receiving care) (name of provider)

Date: _____ _____

(Signature(s) of primary caregiver(s)

Respite Program

FAMILY RESPONSE CARD

Your Name: _____ Phone: _____

Name of Person Receiving Care: _____

Date(s) of Respite Instance: _____ Hours: ____ to ____

Name of Provider: _____

Were you satisfied with the quality of care? ____ yes ____ no

Why or why not: _____

_____

Skill of the provider was: ____ excellent ____ good ____ poor

Do you want this provider again? ____ yes ____ no

Was person receiving care satisfied with care? ____ yes ____ no

PROVIDER RESPONSE CARD

Your Name: _____ Phone: _____

Name of Person Receiving Care: _____

Location: _____ (e.g., in family's home, etc.)

Date(s) of Respite Instance _____ Hours: ____ to ____

Please comment on any problems or concerns about this respite instance:

_____

Would you like to provide respite for this family again?

____ yes ____ no

Why or why not? _____

ADD

Advocates with persons who are Developmentally Disabled

1800 East La Veta Orange, CA 92666

FREE RESPITE CARE SERVICE

WHAT: Temporary relief for parents and families of developmentally disabled persons without regard to age, sex, race, religion or handicap.

WHO: ADD is a non-profit group of Christians in Orange County whose committment is to share their lives with persons who are developmentally disabled. ADD's respite care volunteers have been specially trained to provide this service

WHERE: Serving Orange County, respite care may be provided in your own home, or the home of the respite care volunteer

WHEN: Respite care can be provided for an hour, a day, or a weekend, depending on your need

WHY: Providing this service that is so desperately needed is one way ADD serves the developmentally disabled and their families within our community

For more information, please contact the ADD office : (714) 771-1463

YES, I AM INTERESTED IN RESPITE CARE

I understand this service is offered free by trained volunteers of ADD

☐ I am interested in receiving your respite care service

☐ I am interested in becoming a respite care volunteer

☐ I would like to make a contribution to ADD's respite care program

Name: _____

Address: _____

Phone #: _____

Mail the bottom portion to: ADD 1800 East La Veta Orange, CA. 92666

Your contribution is tax deductable.

supported in part by : Easter Seals U.

UNITED CEREBRAL PALSY ASSOCIATION OF NASSAU COUNTY, INC.

announces the

FAMILY COOPERATIVE RESPITE DEMONSTRATION PROGRAM

***RESPITE* is:**

- RELIEF
- A TIME FOR FAMILIES TO GIVE EACH OTHER A BREAK
- A TIME FOR FAMILY OUTINGS
- A TIME TO RUN ERRANDS
- A HELPING HAND DURING AN EMERGENCY
- OR . . . JUST A FEW HOURS OF FREE TIME

THERE IS NO FEE

INTERESTED IN PARTICIPATING?

WANT TO KNOW MORE?

FOR FURTHER INFORMATION CONTACT:

ROBERT E. PASFIELD, RESPITE COORDINATOR

UCP NASSAU

380 WASHINGTON AVE., ROOSEVELT, NY 11575

(516) 378-2000, EXT. 286

UNITED CEREBRAL PALSY ASSOCIATION OF NASSAU COUNTY, INC.

announces the

COMPANION/RESPITE CAREGIVER PROJECT

LEND A HELPING HAND

Would you like to assist a person who is disabled?

Would you like to earn money while offering "respite" or relief to a family with a disabled member?

Would you like to receive free training in the care of the disabled?

IF SO . . . THEN APPLY TO THE

COMPANION/RESPITE CAREGIVER PROJECT

WHO IS ELIGIBLE TO PARTICIPATE IN THE PROJECT?

- This program is designed to train teens, para-professionals, college students, senior citizens, and others interested in becoming qualified to care for disabled individuals.

WHAT WILL BE EXPECTED OF ME?

- Attend 12 three hour training sessions.
- Show competency in course content.
- Provide 10 hours of "free" service.

HOW WILL I BENEFIT?

- You will receive a certificate.
- Your name will appear in a county-wide directory of qualified caregivers who can be called by families of the disabled.
- You will receive a stipend of $140.00

FOR APPLICATION AND INFORMATION CONTACT:

ROBERT E. PASFIELD, RESPITE COORDINATOR

UCP NASSAU

380 WASHINGTON AVENUE, ROOSEVELT, N.Y. 11575

(516) 378-2000, Ext. 286

TRAINING PROGRAM — FALL 1984

Appendix B
Sample Training Programs

TOPIC	RESPONSIBLE PERSON	AMOUNT OF TIME	TYPE OF PRESENTATION	MATERIALS/ EQUIPMENT	OBJECTIVES
1. Registration	Respite Coordinator and Advisory Council	30 min.	-Informal -Serve refreshments	Nametags; pens or pencils; Registration sheet; Handouts in folder	-To develop a list of persons attending the workshop -To distribute materials in folder -To identify families and volunteers and introduce them informally
2. Welcome and comment on background of respite program	Pastor and/or Respite Coordinator	1 hour	Introduction of everyone present -Lecture and/or slide presentation	Blackboard; screen; slide projector; extension cord	-To formally introduce participants -To define respite -To outline the need for and goals of the respite program -To briefly describe respite models -To 'walk through' materials in golders
3. Needs and feelings of families and person(s) receiving care	Family members, others living with a disabled or frail-elderly person, and/or person to receive care	1 hour	-Panel Discussion		-To share joys and stress of living with a person who is disabled or frail-elderly -To gain insight into feelings of families and persons receiving care -To describe situations where respite can be helpful (e.g., planned vacations, emergencies, etc.)
4. a. Attitudes of providers toward persons with disabilities and persons who are frail-elderly	Pastor, Social worker, Psychologist, or Special education teacher	30-45 min minutes	-Lecture -Small group discussion and/or small group activities	Whatever is requested by speaker	-To provide an understanding of what it is like to have a disabling condition -To determine whether a basically positive attitude exists among providers
b. Overview of types of disabilities and special needs of the elderly	Nurse, Social Worker Psychologist, Special education teacher, or University Instructor	30-45 minutes	-Lecture	Whatever is requested by speaker	-To provide a factual orientation to handicapping conditions and special needs of persons who are frail-elderly

TOPIC	RESPONSIBLE PERSON	AMOUNT OF TIME	TYPE OF PRESENTATION	MATERIALS/ EQUIPMENT	OBJECTIVES
5. Communication	Speech Therapist, Special Education Teacher, and/or Family Member	30-45 min.	-Lecture -Small group discussion and/ or small group activities	Whatever is requested by speaker	-Define Communication -Describe different forms of communication (e.g., verbal and non-verbal) -Give ideas for activities which enhance communication with person receiving care
6. Positioning, lifting and transferring	Physical Therapist, Nurse, and/or Family Member	1 hour	-Lecture -Demonstration practice sessions	Wheelchair; mat or blanket for positioning demonstration any adaptive equipment appropriate to persons receiving care	-To describe and demonstrate procedures for assisting a person in a wheelchair or bed
7. Dressing eating, bathing and toileting	Occupational Therapist, Physical Therapist, Special Education Teacher, and/or Family Member	1½ hours	-Lecture -Demonstration -Practice Sessions	Any adaptive equipment (including braces and clothing) used by persons receiving care	-To describe how breaking each task/ skill down into its basic components can help persons take care of basic needs -To emphasize the relationship between developmental level and skill ability (especially for children) -To demonstrate procedures used for assisting persons with basic needs
8. Basic Emergency and health care by the non-professional	Physician, Nurse, Emergency Medical Technician, or Red Cross Instructor	1 hour	-Lecture -Demonstration -Discussion	Related medical supplies; forms appropriate to safety and liability issues	-To describe and demonstrate treatments for common household injuries -To describe procedures to follow during seizures -To discuss management of basic health problems (e.g., fever, flu, sore throat, vomiting, diarrhea)

TOPIC	*RESPONSIBLE PERSON*	*AMOUNT OF TIME*	*TYPE OF PRESENTATION*	*MATERIALS/ EQUIPMENT*	*OBJECTIVES*
9. Following medication instructions	Physician or Nurse	30 minutes	-Lecture -Discussion	Handouts and/or 'Permission to Give Medication Form	-To describe basic considerations in following medication instructions
10. Leisure and play activities	Physical Education Teacher, Recreation Therapist, Art Therapist and/or Music Therapist	1 hour	-Lecture -Demonstration -Group participation (including the creation of new games and activities)	-Related recreational materials	-To suggest and demonstrate age appropriate activities for children and adults -To encourage an attitude of playfulness
11. Special diets and snacks or meal and snack planning	Dietician, Home Economist, Nutritionist, or Family Member	1 hour	-Lecture -Discussion -Appropriate Foods	-Handouts -Films -Whatever is requested by the speaker	-To describe various special diets appropriate to persons receiving care -To describe or demonstrate preparation of snacks or meals -To teach how to plan meals or snacks

United Cerebral Palsy Association of Nassau County, Inc.

COMPANION/RESPITE CAREGIVER PROJECT TRAINING SCHEDULE

SESSION	*TOPIC*	*INSTRUCTOR*	*DATE/LOCATION*
1.	Introduction Orientation to Cerebral Palsy and other Disabilities Normalization	Project Coordinator Physician As appropriate	Thursday, September 6 Auditorium
2.	Communicating with Families	Social Worker/Psychologist	Saturday, September 8 Auditorium
3.	Handling/Positioning	Physical Therapist	Thursday, September 13 Auditorium
4.	Lifting/Transferring	Physical Therapist	Saturday, September 15 Auditorium
5.	Feeding	Speech Therapist and Occupational Therapist	Thursday, September 20 Auditorium
6.	Medical Emergencies (Medications, Seizures, etc.)	Nurse/Physician	Saturday, September 22 Auditorium
7.	Toilet Training	Occupational Therapist/ Teacher	Saturday, September 29 Auditorium

8.	Dressing/Undressing	Occupational Therapist	Thursday, October 4 Auditorium
9.	Adaptive Equipment	Equipment Specialist	Thursday, October 11 Auditorium
10.	Recreation/Leisure	Recreation Therapist	Saturday, October 13 Auditorium
11.	Communication	Speech Therapist	Thursday, October 18 Auditorium
12.	Behavior Management Examination and Wrap-Up	Psychologist Project Coordinator	Saturday, October 20 Auditorium

NOTE: Thursday evening classes will be held—6:30 PM-9:30 PM
Saturday morning classes will be held—9:00 AM-12:00 NOON

ALL CLASSES WILL BE HELD AT:
United Cerebral Palsy Treatment and Rehabilitation Center
380 Washington Avenue, Roosevelt, NY 11575
Robert E. Pasfield, Respite Coordinator

Appendix C
Building the Respite System: A Developmental Time Line

Building the Respite System: A Developmental Time Line

1. Begin recruitment of Administrative Council members; define program goals.
2. Select the respite coordinator.
3. Respite coordinator and pastor prepare to introduce the respite program idea to the congregation using "Survey of Need" (See Appendix A).
4. Distribute "Survey of Need" forms at Sunday service and/or send them to local agencies.
5. Find out about existing respite programs in the community and make a list of what is available.
6. Organize small gatherings to sensitize the congregation to the need for a respite program; contact families who have returned the "Survey of Need" and invite them to the gathering in their locality; have families fill out *Respite Program Applications;* complete organization of the Administrative Council.
7. Prepare or send for volunteer training materials and set tentative dates for the first training workshop; involve families in planning the training workshop.
8. Recruit volunteers from the congregation and community; begin outreach.
9. Inform community of the proposed respite program.
10. Hold training workshop; match families and respite providers.
11. Arrange for in-home visits.
12. Follow-up with families and providers to evaluate success of respite instances.
13. Develop volunteer support network.
    a. Facilitate social events for volunteers.
    b. Organize social events for families and volunteers. (Provide respite care for families during these events.)
    c. Arrange for continuing education of volunteers, according to the changing needs of both families and volunteers.

14. Hold periodic group meetings with families for evaluation purposes.
15. Conduct a yearly review and evaluation of the overall system. (May be a joint effort of the respite coordinator, pastor and Administrative Council.)

Annotated Bibliography

PROGRAM DEVELOPMENT MATERIALS

Family Support Services: Respite, Sitter, In-Home Program Handbook. 1979

Describes the services provided by sitter/companions, paid respite care providers, in-home trainers, and homemakers. Discusses recruitment and eligibility of families, and certification and payment of respite providers. Written agreement between a family and sitter includes a screening interview for homes and certification of respite provider. Recipients of services are persons with developmental disabilities and their families.

Available from: Arizona Department of Economic Security, Phoenix Division of Developmental Disabilities and Mental Retardation Services, Support and Licensing Manager, 3727 East McGowell, Phoenix, Arizona 85006.

Lindsay/Ferguson Associates, *Introducing the Respite Care Co-op Program.*

Provides a tape-guidebook kit for introducing the program. Will also provide training and technical assistance in starting and operating a care co-op program.

Available from: Lindsay/Ferguson Associates, 2324 West Main Street, Kalamazoo, Michigan 49007.

Moore, C. and Seashore, C. N., *Why Do Families Need Respite Care? Building A Support System.* June 1977.

This article is a realistic, easy-to-read justification for developing a respite care program. Among the support systems described are: role models, persons in similar circumstances, close friends, skilled problem solvers, people who respect the individual in need, information agents, and those who are an inspiration to the families who need assistance. Discusses assessment of a family's support system.

Available from: Montgomery County (Maryland) Association for Retarded Citizens, Family and Community Services, 11212 Norris Drive, Silver Spring, Maryland 20902 or Eric Document Reproduction Service, POB 190, Arlington, Virginia 22210 (Order Number ED-145614).

A Better Answer . . . Homemaker-Home Health Aide Services for the Person with Developmental Disabilities and Family: A Handbook for the Homemaker-Home Health Aide. 1981.

This looseleaf notebook is a training manual for home health aides who work with children and adults with developmental disabilities. Chapter topics include: personal care, nutrition, recreation activities for the teenager and adult, adaptive and assistive devices, and sexuality. An instructor's manual accompanies the training manual.

Available from: National Home Caring Council, Inc., 67 Irving Place, 6th Floor, New York, New York 10003.

Cohen, Dr. Shirley and Warren, Rachel, *Respite Care: Supporting Families of Developmentally Disabled Persons.* 1984

This book provides comprehensive coverage of all aspects of respite care including the selection and training of workers, legal and fiscal perspectives, how to start and operate a program, and respite care for families of the elderly, the terminally ill, and other dependent populations.

Available from: Pro-Ed, 5341 Industrial Oaks Blvd., Austin, Texas 78735.

Dickman, I. and Warren, R., *For This Respite. Much Thanks.* 1981.

This book describes respite programs throughout the United States. Chapters deal with such topics as: program start-up, development of community resources, and family involvement. Includes a listing of resource materials.

Available from: Professional Services Program Department, United Cerebral Palsy Associations, Inc., 66 East 34th Street, New York, New York 10016.

Extend-A-Family

This handbook describes the policies and procedures of the Extend-A-Family program in which "host" families provide short-term care in their homes for children up to eighteen years of age who are mentally retarded.

Available from: Extend-A-Family, 35 Lytton, Toronto, Ontario MAT 2G1 Canada.

Princeton Theological Seminary Libraries
1 1012 01176 5841

McPeake, J., Bard, C., Sellers, D., and McClellan, R., *Time For Me: Respite Training Manual.* 1981.

This excellent training manual for respite providers contains chapters on the following topics: attitudes toward the developmentally disabled, overview of developmental disabilities, communication, physical management and adaptive equipment, feeding techniques, behavior management, leisure time activities, first-aid and general health care, feelings and needs of the family, "hands-on" and home visits.

Available from: United Cerebral Palsy, 318 Water Street, Akron, Ohio 44308.

Murphy, Judith, *Home Care of Handicapped Children: A Guide.* 1982.

This series of guidebooks deals with home care of children aged three to twelve with such disabilities as: mental retardation, orthopedic handicaps, visual impairment, hearing impairment, epilepsy, diabetes, hemophilia, cystic fibrosis, cleft palate and cleft lip, autism and asthma. Each guidebook contains sections on: characteristics of the specific disability, basic child health, new learning, play, safety and protective measures, and hints on caring for and understanding a child with that particular disability.

Available from: Lutey Publishing Company, North Star Route, Lyons, Colorado 80540.

Safety and Handling (Wheelchair). 1976.

This booklet contains helpful hints about handling a wheelchair, including: going up and down curbs and steps, transfer activities, transporting a wheelchair in an automobile and safety inspections.

Available from: Everest & Jennings, 3233 Mission Oak Blvd., Camarillo, California 93010.

Stock, C. and McClure, J., *The Household Curriculum: A Workbook for Teaching Your Young Child to Think.* (New York: Harper & Row Publishers, 1983.)

This book is written for care providers of children aged three to five. Materials found in any home are used in a playful manner to help children develop such skills as eye-hand coordination, sound discrimination, memory, and language.

Adults in the Church

SHARING CARE

The Christian Ministry of Respite Care

Judith K. Murphy, Ed. D.

This manual provides all the information necessary for a church or other organization or group to become active in providing on-going temporary relief to those who are primary caregivers to the disabled, frail, elderly, or homebound. This respite, or relief, is necessary for the primary caregivers to relieve, if only for a short while, the burden of routine medical care and the attendant stresses, and to allow them some time for renewal. Included are a bibliography, resource lists, and sample forms.

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